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# **Consumer Attitudes About Health Information Infrastructure**

**William A. Yasnoff, MD, PhD, FACMI**  
**Managing Partner, NHII Advisors**



# **Consumer Attitudes About Health Information Infrastructure**

- I. General attitudes about a system of electronic health records**
- II. Value & uses of electronic health records**
- III. Privacy & trust issues about electronic health records**
- IV. Consumer principles for system design**

# **I. General attitudes about a system of electronic health records**

# I.A. Nationwide Health Information Exchange

- **Yes: 72%**
  - **Strongly favor: 38%**
  - **Somewhat favor: 34%**
- **No: 23%**
  - **Strongly oppose: 12%**
  - **Somewhat oppose: 11%**
- **Source: Public Opinion Strategies**
  - **800 likely voters, Sept. 2005**
  - **Margin of error +/- 3.46%**

# **I.B. Absolute Top Priorities**

- **91%: Identity of all users would be carefully confirmed**
- **81%: Individuals could review who has had access to their records**
- **79%: Access to an individual's records would require their permission**
- **72%: Individuals would NOT be denied care or financially penalized based on failing to provide information or not participating**
- **68%: Employers would NOT have access**

# **I.B. Absolute Top Priorities(cont.)**

- **53%: An individual's complete health and medical history would be accessible to that person over the Internet in a secure account**
- **50%: Individuals specifically control what information is available to others (e.g. history of mental health treatment could be suppressed)**
- **38%: Independent bodies, accountable to the public, would govern health information exchange with consumer participation as full voting members**

## II. Value and uses of electronic health records

## **II.A. EMRs improve quality, reduce errors**

- **Yes: 80%**
  - **Strongly agree: 52%**
  - **Somewhat agree: 28%**
- **No: 18%**
  - **Strongly disagree: 8%**
  - **Somewhat disagree: 10%**



## **II.B. De-identified database from EMRs provides up-to-date medical information and expanded knowledge**

- **Yes: 81%**
  - **Strongly agree: 47%**
  - **Somewhat agree: 34%**
- **No: 17%**
  - **Strongly disagree: 6%**
  - **Somewhat disagree: 11%**

## **II.C. How would you use secure online records?**

- **69%: Check for mistakes in medical record**
- **68%: Check & fill prescriptions**
- **58%: Get results over the Internet**
- **57%: Conduct secure & private email communication with your doctor(s)**

## **II.D. Getting records quickly in emergency could be difference between life & death**

- **Yes: 71%**
- **Never thought about it before: 53%**
- **Source: Connecting for Health**
  - **2004 survey**
  - **N = 1,750**

## **II.E. Emergency room doctors should have access to my electronic medical records to reduce treatment errors**

- **Yes: 93%**
- **Source: Accenture Survey, 2005**
  - **519 U.S. health care consumers (seen physician in last 10 years)**

## **II.F. Willing to pay at least \$5/month to have my medical records stored in electronic format**

- **Yes: 52%**
- **Source: Accenture Survey 2005**

# **III. Privacy & trust issues about electronic health records**

# **III.A. How concerned are you about the privacy of your medical records?**

- **Concerned: 67%**
  - **Very concerned: 36%**
  - **Somewhat concerned: 31%**
- **Not Concerned: 34%**
  - **Not very concerned: 19%**
  - **Not at all concerned: 15%**
- **Source: California Health Care Foundation, 2005**
  - **2,100 U.S. residents over age 18**
  - **California oversampled (N~1,000)**

## **III.B. Concerned that claims information might be used by employer to limit job opportunities**

- **2005 Survey: 52%**
- **1999 Survey: 36%**



## **III.C. 13% of Consumers have used privacy-protective behaviors**

- **Asked a doctor not to record a health problem or record a less serious/ embarrassing diagnosis**
- **Gone to another doctor to avoid telling regular MD about a health condition**
- **Personally paid for a test, procedure, or counseling rather than submit a claim out of concern someone else would access information**
- **Decided not to be tested out of concern that others might find out about the results**

# **III.D. What web service provider would you trust most to keep your online medical record private and secure?**

- Doctor site: 57%
- Health Insurance site: 14%
- Government site: 12%
- Commercial site: 8%
- Non-profit site: 7%
- Employer site: 2%
  
- Source: Connecting for Health
  - 2003 online survey, n = 1,246

# **IV. Consumer Principles for System Design (15 organizations)**

- 1. Consumers have access to their information**
- 2. Consumers control access to their information**
- 3. Consumers may delegate access control**
- 4. Consumers are informed about how their data may be used/shared**
- 5. Consumers may review names of entities that have had access to their information**
- 6. Information integrity, security, privacy, and confidentiality is protected**
- 7. System has independent oversight**
  - Accountable to public**
  - Full voting participation of consumers**

# Organizations Endorsing the Consumer Principles for System Design

AARP

ACOR Š Association of Cancer Online Resources

AFL-CIO

American Hospice Foundation

Center for Medical Consumers

Consumers Union

Families USA

Health Privacy Project

International Association of Machinists and Aerospace Workers

Markle FoundationŠ Personal Health Technology Council

Maternity Center Association

National Coalition for Cancer Survivorship

National Consumers League

National Partnership for Women and Families

SEIU Š Service Employees International Union



# Questions?

**William A. Yasnoff, MD, PhD, FACMI**  
**[william.yasnoff@nhiiadvisors.com](mailto:william.yasnoff@nhiiadvisors.com)**  
**703/527-5678**

# References

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- [http://www.connectingforhealth.org/resources/phwa\\_survey\\_6.5.03.pdf](http://www.connectingforhealth.org/resources/phwa_survey_6.5.03.pdf) (2003)

## ■ California Health Care Foundation Survey (2005)

- <http://www.chcf.org/privacy>

## ■ Accenture Survey (2005)

- <http://www.accenture.com/xd/xd.asp?it=enweb&xd=dyn%5Cdynamicpressrelease857.xml>

## ■ Consumer Principles (2005)

- [http://www.phrconference.org/assets/consumer\\_principles\\_101105.pdf](http://www.phrconference.org/assets/consumer_principles_101105.pdf)

